

The Caregiver

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NORTH CAROLINA ALZHEIMER'S ASSOCIATION NEWS

Eastern NC Alzheimer's Association – Caregiver Education Conferences – 13 regional conferences will be offered during 2004. These conferences will offer the best and latest information on Alzheimer's research, diagnosis and treatment, and care. Please contact Eastern North Carolina Chapter at 1-800-228-8738 or check out the website at www.alznc.org for locations and dates.

Western Carolina Chapter Alzheimer's Association – March 18th & 22nd and May 20th—Partnering With Your Doctor: A Workshop for Persons with Memory Problems and Their Care Partners. May 25th—Activity based Alzheimer Care: Building a Therapeutic Program – details to be announced. Dementia specific courses are offered for 3 hours of continuing education credit by NC Division of Facility Services. All professionals are welcome. Cost per course \$10/person. Preregistration is required. Contact Beth Croom at Western Carolina Chapter for more information.



Vascular Cognitive Impairment- Clues to Prevention of Late Life Dementia

Kathleen A. Welsh-Bohmer, Ph.D.
Professor of Medical Psychology
Department of Psychiatry
Associate Director of Bryan ADRC

Nearly one hundred years has passed since the renowned German neuropathologist and psychiatrist Alois Alzheimer (1864-1915) originally described the brain neuropathological findings of his patient, Auguste D, a 54-year-old woman with progressive dementia. In 1907 his reported findings of plaques and tangles in the cortical brain structures of his patient, led to the recognition of a common chronic brain degeneration disease of aging, which now bears his name, Alzheimer's disease (AD). Recently, a wonderfully well-written historical overview summarizes the early work in this area of brain research (Reed, 2004; Archives of Neurology, 61: 433-435). With this historical perspective I am reminded of the biblical phrase that is now a cultural polemic: *"What has been will be again, what has been done will be done again; there is nothing new under the sun."* The overview of Reed underscores a less well-known historical note, that Dr. Alzheimer also recognized the importance of vascular changes in the aging brain, not just AD pathology. Dr. Alzheimer described the vascular brain changes often seen in aged brain, and had posited that these changes may give rise to progressive dementia, separate from the changes associated with AD. He recognized 100 years ago issues with which we still grapple to understand today, the relationship of AD to vascular disease and dementia of later life.

Although the relationship of vascular disease to AD may not be a new topic, what has transpired over the last century is a much better understanding of the interaction of these two conditions. Observational studies, such as a large population based study in Utah of aging and dementia: the Cache County Study of Memory and Aging¹ (CCMS; PI Kathleen Welsh-Bohmer) have begun to underscore the factors that influence both AD and vascular dementia. Recently, the CCMS study reported on reduced incidence of AD with antioxidant vitamins E and C, vitamins that have also shown benefit in mitigating risk of vascular dementia (see Zandi et al., 2004 for review). The hope is that by understanding both conditions and the common factors they share, medical science will be in a position to treat and eradicate them both as public health menaces of late life. The intent of this article in *The Caregiver* newsletter is to familiarize the reader with the notion of "vascular cognitive impairment," its relationship to Alzheimer's disease, and the possibilities ahead in preventing both disorders.

So what is Vascular Cognitive Impairment? How is Vascular Dementia different from Alzheimer's disease?

Vascular Cognitive Impairment (VCI) forms a spectrum of disorders that relate to small and large vessel disease in the brain. At one end of the continuum is "Vascular Dementia," sometimes also called multi-infarct dementia. At the other end, are subtle cognitive disorders that

are tied to small stroke or to subacute vascular events such as chronic ischemia. This more subtle disorder has been referred to as “vascular cognitive impairment - not dementia” or Vascular CIND (Bowler, 2002).

Vascular dementia (VaD) is a common and leading cause of dementia in late life. As most studies in this country show, Alzheimer’s disease is the most common cause of dementia, accounting for over 60% of the cases. However, nearly 25-30% of the late-life dementias have a vascular component, either in isolation or in conjunction with AD pathology. It is the 2nd largest contributing cause to late life dementia and because of its common co-occurrence with AD, there is a question as to whether the two conditions share basic mechanisms.

The diagnosis of a vascular dementia, rests first on the confirmation of “dementia” and then determining whether a vascular event has occurred. Commonly, the following diagnostic features are needed to allow the most secure diagnosis of a vascular dementia:

- Confirmed dementia (defined as memory difficulties and problems in at least other areas of thinking: language expression, abstraction, visuospatial judgment etc.
- Focal findings on the neurological examination to suggest that a stroke has occurred
- History of a known or suspected acute stroke event
- Onset of cognitive problem within three months of the stroke event or in the absence of this history, the course is rather “stepwise” in nature

Brain Magnetic Resonance Imaging (MRI) studies or Computed Tomography (CT) scans are not necessary for the diagnosis but they do provide important supportive information. On brain imaging, the physician would be looking for either completed strokes (large or small) in the cortical gray matter or deep brain structures or for evidence of ischemic changes in the deep white matter pathways.

Vascular cognitive impairment without dementia (Vascular CIND) is a heterogeneous syndrome affecting approximately 3-5% of the population over age 65 (Rockwood et al., 2000). Vascular CIND is qualitatively similar to vascular dementia but differs from it in the severity of symptoms. In general, the disorder is characterized by more modest cognitive impairment in the context of vascular events. Importantly, the individual is not demented. That is, the cognitive impairment may be rather contained and easily ascribed to a known stroke location. Alternatively, the problem may involve many different cognitive functions, but the difficulties are considered of minimal consequence and the individual is still able to carry out all activities of daily function in spite of it. With the enhanced methods for neuroimaging the brain, such as through MRI, small vessel disease and white matter ischemic changes can be readily observed. A continuum of these changes has been described, leading some to suggest that extensive white matter change may represent a chronic and rather indolent vascular process in the brain. These vascular changes may evolve and include completed strokes, leading to cognitive changes and ultimately dementia.

How are the conditions distinguished from AD?

Diagnostically, a slowly progressive dementia in the context of a known stroke or other vascular disease may be very difficult to distinguish from Alzheimer's disease, which itself is a slowly progressive dementia. The conditions can be partially distinguished by the neuropsychological presentations (see Table 1). Alzheimer's disease dementia is from its outset characterized by a profound difficulty in learning and retaining new information. This leads to a very rapid forgetting of newly learned information and results in tremendous impairments in daily function. Memory disorders in vascular disease tend to be less severe in nature and often described as patchy or inconsistent. The individual may be able to retain some recent events exceptionally well but other events, occurring in roughly the same time frame, may be forgotten. In daily life and in testing situation, the condition can resemble AD in a complete inability to recall what was just learned, however, unlike AD the information is not actually lost but simply inaccessible. With partial reminder cues, the individual is often able to recall the information which appeared to have been lost from memory. Beyond memory, vascular conditions often are characterized by difficulties in what are called "executive behaviors," the ability to think abstractly and flexibly and to inhibit incorrect responses.

**Table 1: Neuropsychological Features
Vascular CIND vs early AD**

Vas CIND	AD
<ul style="list-style-type: none"> • Memory impaired; recognition relatively preserved (benefit from retrieval support) • Working memory impaired • Dysexecutive syndrome <ul style="list-style-type: none"> ◆ Decreased inhibitory control behaviors ◆ Decreased flexible thought • Psychomotor slowing • Attentional impairments 	<ul style="list-style-type: none"> • Pronounced problems in recent memory; little benefit from retrieval cues • Working memory OK • Mild dysexecutive <ul style="list-style-type: none"> ◆ Decrease in some types of fluency (e.g. animals) ◆ Naming deficient • No motor slowing • No attentional compromise

Table 1: Neuropsychological features that distinguish mild vascular cognitive impairments which are not yet dementia (Vascular CIND) from early stage AD.

It should be noted that part of the difficulty in distinguishing between VaD and AD, is because the two conditions frequently co-occur together. As noted previously nearly 1/3 of the dementias have mixed etiology. Consequently, trying to tease apart the VaD from AD in this setting will be futile when elements of both disorders are present. For years, there was a firm belief that the two conditions were separate. And although this is most certainly true, the overlap between the conditions is important to acknowledge as this observation may produce mechanistic clues to the pathogenesis of both disorders. In epidemiological studies that have followed individuals over a number of years, it is clear that stroke increases risk for dementia generally and AD in particular (Honig et al., 2003; Hayden et al., 2004). In most current series, the risk of developing dementia after a stroke is about 2 times higher than for those without a stroke. It is

now becoming clear, that many of the risk factors known for vascular disease, such as hypertension and diabetes, are now also proving to be related to an increased risk for AD.

Can vascular cognitive impairment be prevented?

As already discussed, recognizing the interaction of vascular conditions and Alzheimer's disease may provide critical clues to the underlying mechanisms of these brain conditions and lead to the development of effective treatment and ultimately prevention strategies. To date there is no confirmed treatment to prevent the development of AD pathology (i.e. plaques and tangles). However, stroke risk can be modified to some extent. Consequently, a rationale is that by tackling vascular disease, AD dementia risk and vascular dementia risk may be lowered concurrently.

The current interventional approaches to reducing dementia risk – whether vascular in nature or AD- emphasize the rule: “What’s good for the heart is good for the head!” Commonly, this translates into recommendations of dietary and lifestyle changes emphasizing a heart smart, healthy diet along with moderate exercise. To reduce risk of stroke or cardiovascular disease, maintaining a healthy weight is important as is the elimination of smoking habits. When dietary approaches are not successful in controlling diabetes, cholesterol, or blood pressure, medical management with medications may be needed. This may include use of baby aspirin, antioxidant vitamins and other supplements as needed.

Treatment trials in AD are underway currently to explore medications that control cardiovascular and cerebrovascular risk conditions, such as diabetes. In 2001, Glaxo Smith Kline (GSK) began studies of its drug, Avandia, on cognitive decline, dementia, and AD in older adults. The drug, commonly used to treat adult onset diabetes by controlling blood sugar levels, has shown promise in animal models and in some human studies of memory. No information is yet available from these clinical trials, but more of such treatment approaches can be likely anticipated in the future, as scientists continue to unravel the biological interface between cerebrovascular disease and AD.

Citations

- Bowler, JV (2002). Concept of vascular cognitive impairment. *Journal of the Neurological Sciences*, 203: 11-15.
- Hayden, K.M. et al (2004). Stroke and risk of AD. Letter to editor. *Arch Neurology*, in press.
- Honig, L.S. et al (2003). Stroke and the Risk of Alzheimer Disease. *Arch Neurology*, 60:1707-1712
- Reed, B.R. (2004). Vascular dementia. *Archives of Neurology*, 61: 433-435.
- Rockwood et al (2000). Prevalence and outcomes of vascular cognitive impairment. *Neurology*, 54:447-451.
- Zandi, PP et al (2004). Reduced risk of AD in users of antioxidant vitamin supplements: The Cache County Study. *Archives of Neurology*, 61: 82-88.

¹ The Cache County Memory Study is a large collaborative project, continuously funded since 1994 (NIA: AG AG11380) and involves collaborators at Utah State University (where the population resides and all the primary data collection occurs), Duke University, Johns Hopkins, and the University of Washington-Seattle. The study is designed to examine health conditions of aging, namely cognitive disorders associated with AD, stroke, and neurological disorders.

**Alzheimer's 2004: Targeting the Epidemic
Candid Conference Clips**



Dr. Schmechel lays out the future of genomic medicine.



Dr. Karlawish suggests key questions to guide diagnostic disclosures.



Ms. Clements convinces conference participants that Alzheimer's has to "keep up" with her.



A patient's perspective on research participation.

Candid Conference Clips



A mother and daughter describe their experience with genetic family studies.

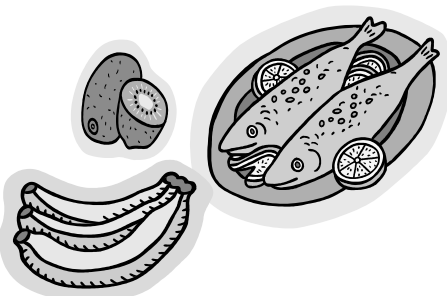
Dr. Manly answers informal questions about the effects of education on cognitive testing.



Drs. Sano and Welsh-Bohmer highlight what we need to know to prevent or delay memory symptoms.

Margaret Hicks of Shelby, NC describes her mother-in-law's needs to a Life Enrichment Center staff member in a workshop dramatization of adult day services in action.





Brain-wise/ Heart-wise Dietary Recommendations

by Patrick M. Sullivan, Ph.D.
Bryan ADRC Lab Tour 2/11/04

The newly revised USDA food pyramid is a good model for a healthy diet, but it is short on details. Here I hope to provide a more detailed description of which foods are considered beneficial and which ones to avoid. Multiple research studies continue to investigate which type of foods lead to a decreased risk of dementia. Our research consistently shows that a healthy diet can reduce the risk of Alzheimer's disease*. Unfortunately, a healthy dietary practice may have no effect on people with rare inherited (familial) mutations. Treating these people will require alternative measures.

There are three major themes that are important to remember while following these recommendations:

MODERATION, REDUCE CALORIC INTAKE, WHOLE FOODS

MODERATION: This is a concept we are all familiar with, however, most people have difficulty practicing. Moderating your sugar and alcohol intake makes sense to most people; however, it's also important to moderate those foods that are good for you. For example, consuming too much spinach or fish (which have clear health benefits) can lead to adverse health consequences (the same as consuming too little).

REDUCE CALORIC INTAKE: Research has shown over and over again that caloric restriction leads to a very significant decrease in many diseases, which leads to an increase in lifespan. The problem is human beings are incapable of habitually reducing their caloric intake by 30-40%. The take-home message should not be lost, however, and so any significant reduction in calories is beneficial.

WHOLE FOODS: Over the last 40-50 years, our society has moved away from whole foods and embraced the convenience of fast, processed foods. This has led to the introduction of trans-fatty acids (man made fat), refined carbohydrates (stripped of all nutrients) and many other potentially toxic chemicals in processed foods. Consuming a diet of whole or natural foods is clearly more beneficial for our body.

Here is a list of foods, ordered by the quantity in which they should be eaten (from high to low). Remember, serving sizes are less important than a well balanced food regimen, with an emphasis on reduced caloric intake.

*There is substantial evidence to suggest that dietary recommendations for reducing the risk of dementia may also work to reduce the risk of heart disease, diabetes, macular degeneration and stroke.

Whole grains:

Brown rice, oatmeal, popcorn, barley and whole wheat.

Good source of thiamine (vitamin B1) and fiber

Vegetable oils:

Canola, corn, soy and olive oils.

No cholesterol, low saturated fat, high omega-3 fat content, provides essential level of omega 6 fats.

Vegetables and Fruits:

The darker and richer the color the better: Spinach, tomatoes, carrots, broccoli, mangos, cantaloupe, oranges, apricots, strawberries and blueberries.

Good source of natural anti-oxidants, essential vitamins (folic acid, B6 and B12) minerals and fiber. Also lowers homocysteine and cholesterol levels.

Nuts and Legumes:

Almonds, pecans and walnuts; green beans and kidney beans.

Good source of omega-3 fat and protein

Fish, Poultry and Eggs:

Cold water fishes (tuna, salmon, mackerel), free range chicken, turkey and eggs.

Good source of omega-3 fat, protein and choline. Note: Free range animals have a higher content of omega-3 fatty acids and lower saturated fat content compared to grain fed animals.

Dairy products:

Yogurt, cheese and milk from free range sources (see note above).

Good source of calcium, protein and vitamins (milk).

Fat Primer: There are basically 4 types of fats: *Trans, saturated, monounsaturated and polyunsaturated fat*. Trans and saturated fats are the types to avoid. Trans fats are man-made, and most saturated fats come from animal products. Omega-3 and omega-6 fats (both polyunsaturated fats) are essential, and therefore are the preferred type of fat.

Foods that should be eaten sparingly:

White rice and high starch foods like potatoes.

Breads, pastries, crackers, pasta and cereals made with refined flour.

Sweets

Red meats, pork and lamb. *Note: Free range animals contain leaner meat which has less saturated fat. Processed beef, like hamburger is bad.*

Foods that should be avoided:

1. Foods containing **partially-hydrogenated oils (trans-fatty acids (TFA))**. The bad news is there are close to 40,000 foods that contain TFA. The good news is that TFA are only found in processed foods* (food industry). Margarine has the highest levels of TFA, and these types of man-made fats are also found in most breads, cereals, fast food and commercially baked/fried foods. An easy way to avoid TFAs is to consume predominantly whole foods. *(note: there are naturally occurring TFAs, which are produced by ruminant animals like cows, however they constitute a very small portion of our diet.)
2. Foods high in **cholesterol***, like liver and other organ meats, egg yolks, some dairy products. *This is not as important for people with average or below average levels of total cholesterol, and a high HDL: LDL ratio.

3. Foods that contain a significant amount of **saturated fat**, like whole milk, ice cream, butter, cream, marbled steaks (e.g. ribeye), hamburger, bacon, sausage, skin of poultry, palm and coconut oils.

Other dietary considerations:

1. Keep calories to a minimum (on average < 2500/day); **Moderate**.
2. Reduce sugar intake (includes foods containing corn sweetener, corn syrup, etc.)
3. Reduce sodium (salt) intake (very high in processed foods).
4. Watch iron intake (multi-vitamins with high iron and processed foods). There is no need for healthy individuals to take multi-vitamins if you eat a balanced diet.
5. Drink several glasses of water/day, instead of commercial sodas.
6. **Moderate** alcohol consumption (1-2 drinks of any type/day) can be healthy for most people. More than 2 drinks/day is harmful.
7. Other examples of foods with high anti-oxidant activity are; garlic, kale, brussels sprouts, broccoli, beets and yams.

Although more rigorous scientific investigations of diet are needed, there are many research studies which support these recommendations. What is healthy for the heart and brain, will surely have added benefits for the rest of your body.

Avoiding Alzheimer's Disease

Donald E. Schmechel, MD, Director and Principal Investigator of Duke's Bryan ADRC appeared live on National Public Radio's The People's Pharmacy on March 13, 2004. The topic was "Avoiding Alzheimer's Disease". The show aired again the following week. A CD is available for \$15 pre-paid from Graedon's People's Pharmacy (#490, March 13, 2004 on Alzheimer's). PO Box 52027, Durham NC 27717-2027. www.healthcentral.com/PeoplesPharmacy/PharmFullText.cfm?ID=60807

Research Participation: An Option Regardless of Where You Live

A nationwide effort funded by the National Institute on Aging (NIA), and supported by the Alzheimer's Association includes 18 NIA-funded Alzheimer's Disease Centers working to identify 1,000 families with at least two siblings who have been diagnosed with late-onset AD (diagnosed at 60 years or older). Collection and analysis of families with multiple affected individuals will help identify risk factor genes and new targets for therapy.

To be eligible to participate in the study, families must have at least 3 living members who can donate blood, including:

- 2 brothers or sisters who developed AD after age 60, *and*
- Another family member **over** age 50 who may have memory loss **OR** a family member **over** age 60 who does **not** have any memory loss.

Participation involves a neurological exam with memory testing or collection of medical records and the donation of a blood sample. All identifying information such as name and date of birth are removed from all materials.

To participate in the study, families should contact NCRAD toll-free at 1-800-526-2839, or by email alzstudy@iupui.edu. Information is also available through the study Website, www.ncrad.org.



Emergency

It's difficult to think straight...

©Judy Ewens, Raleigh, NC

Real emergencies aren't like a media clip, replete with unrelenting, if jerky, images and cacophony. Real emergencies are jagged and uneven: frantic forges an uneasy alliance with queasy calm. And you hear the images long after the sounds fade.

A half hour before moving my husband to a nursing home, my obligatory talk with the director of the "nice" facility exhausts our reservoirs of platitudes and deteriorates into pointless drivel. The phone rings as I rise to leave the office. "Get up there. He's in distress now."

Alone in the elevator. Not too concerned. Define "distress" first.

The elevator door opens on the sight of a rugby scrum of flailing arms and legs and frantic efforts to control them. The awful guttural sounds of a man in the throes of a powerful seizure compete with the curt, conflicting directives of paramedics trying unsuccessfully to subdue him enough to sedate him.

I blow past the officious "Please stand back, ma'am," tunnel under the ring of strangers, throw myself spread-eagle across my husband, and try to do what I've been doing for over 5 years: remain calm, direct traffic, diffuse chaos, create dignity where there is none. I add 95 pounds to the effort to hold his arm steady for the IV needle, dispatch an onlooker to find my purse, try unsuccessfully to prevent his daughter from seeing him like this, insist that she go outside to call the rest of the family. Blood spatters us all, flying from a badly bitten lip and the continuing futile attempts to insert an IV. I finally snap at the reluctant young paramedic trying for the perfect angle to "just do it, for heaven's sake—how much worse off can we be?"

The brief, sweaty silence that marks his success is replaced by sounds of the struggle to fit the gurney into a too-small elevator, followed by fervent swearing as we crawl over, under, and around the gurney, IV line, tubes, and each other to squeeze into a freight elevator. Outside at last, the commotion congeals, as each person does his job, and I am forcibly diverted to the front of the ambulance for the safety of a seat belt. As if I care. The images in my head obliterate the wail of the siren.

The practiced flurry of the ER excludes me, and I am tugged down the hall toward the bored murmur of the business-as-usual office. Forms to complete; insurance cards to photocopy. Can't leave yet. More forms; signatures. Then back to the counterfeit order of the ER. The doctor calls for a ventilator, and I whirl to say, "No, he has an advanced directive." But a nurse rushes over: "It isn't like that; they used anesthetic to stop the seizure, and his airway will collapse; you can always have the ventilator removed if appropriate; and you can't just let him smother, can you?"

I've never seen even a little seizure, never thought about one, never considered that you might die from one. So what's appropriate? I let them treat him. It's difficult to think straight with blood under your fingernails.

Scans are scheduled for later; there's no hurry now; I am to go upstairs to the ICU waiting room. Send his shell-shocked family back to clean out his room to give them something to do, then realize that I have no idea where the waiting room is. Wander off alone through bleak, friendless halls – obediently search for a place I don't want to be, dreading the stew and stir, persistent telephones, and always-on-but-never watched TV that will greet me there. Wherever "there" is.

The waiting room stands empty. The TV whispers an indecipherable babel that someone, some time, mercifully turns off.

And I wait. Still alone. Vaguely aware of the competing ruckus of images and sounds in my head. Wondering if they'll ever blur into silence. Wondering how to get the blood out from under my fingernails.

Postscript: After 4 days in intensive care, Fred Ewens was moved to palliative care in accordance with his advanced directive. He died on October 5, 2002, at the age of 56. A brain autopsy confirmed the cause of death as Alzheimer's Disease.

©2004, Judy Ewens. Reprint with permission of author. This segment was posted on 3/16/04 on <http://www.alzforum.org/dis/car/adexper/ewens.asp>. Please see the site for a picture and background on the author and her husband.

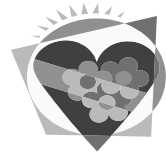


A True Friend of Alzheimer's Families

Rebecca Arrington Barnhill Hundley, of Thomasville NC, died January 6, 2004 in High Point, NC. Her husband, a former mayor of Thomasville, died from Alzheimer's disease.

Ms. Hundley was the first and most sustained major contributor to the Duke Family Support Program. She purchased the first toll-free telephone number and answering machine in 1980 to help connect families to Duke Alzheimer's resources. She funded issues of *The Caregiver* newsletter when there were no state funds to continue the free subscriptions for NC families and professionals. She provided astute state advocacy leadership, as she spoke about her caregiving experience at legislative hearings, support groups and community forums.

Ms. Hundley was a powerful writer, contributing some of the best first-person articles about the burdens and blessings of family care in the first issues of *The Caregiver*. Her writing captured her compassion for the feelings of people with Alzheimer's, as well as for their families. Ms. Hundley remained a tireless advocate for Alzheimer's families until her death. Her husband's children and grandchildren continue that legacy with their Gallo Farm fundraisers for AD research and support. Ms. Hundley's leadership, wise counsel, empathy and compassion will be sorely missed.



Sexuality: An Enduring Component of the Human Experience

By Lauren Willer, Social Work Intern

Twelve years ago, the Duke Family Support Program published the manual, *Sexuality and the Alzheimer's Patient*, which many families continue to use in caring for a person with dementia. Since the publication of this manual, there have been many requests for more specific information for families and care staff about sexuality and dementia in the nursing home. The Duke Family Support Program is in the process of developing a manual for both direct care staff and families about sexuality in the nursing home or residential care facility. We introduce the complexity of the issue of sexuality in residential care in the hope that it will trigger ideas, concerns, or questions from our readers. With input from families and nursing home staff, we hope to create a manual that is practical and relevant to the quality of daily life in a care facility.

Throughout the lifespan, sexuality is part of being human. Each of us has our own history of how we have expressed ourselves as sexual beings. To what extent are we always in tune with our sexuality and our need for physical connection to other people? Our concept of ourselves as sexual beings influences our motivation to seek meaningful relationships, and influences the ways we satisfy our sexual or intimacy needs.

Sexuality is an important component of our relationships and identity. People have different perspectives on the role of sexuality in their lives. One way to think about sexuality is as a way to express love to another person. However, one can love and become intimate in strictly platonic and family relationships. Another perspective is that sexuality is within the domain of the human desire for caring physical touch. Humans need to be touched to stay healthy and thrive. Every person expresses his/her sexuality within the context of individual desires, relationships, values, and culture.

American culture frequently portrays sexuality as the realm of the young, beautiful, and healthy. What are common conceptions about sexuality among people who are at a later stage of life? How do we feel about the sexuality of persons who are ill and dependent? What influences our ideas about the rights of older adults to fulfill sexual desires in relationships? What harmful stereotypes exist about older adults in sexual relationships? Unfortunately, there is a lack of emphasis on this aspect of one's life as one ages, and, specifically for persons in nursing homes or other care facilities.

Nonetheless, families and care staff sometimes find themselves ill prepared and uncomfortable when they must respond to both appropriate and inappropriate sexual behaviors.

As we age, we pay attention to changes in our bodies, our minds, our emotions, as well as our sexuality. There may be challenges to a person's sexual vitality, perhaps as a result of stressful life events, illness or medications, lack of a partner, or a belief that one is too old to be an interesting partner.

There may also be elements of one's life that provide an opportunity for positive evolution of sexual expression. Retirement can mean extra time, relaxation, and attention from a

partner. Maturity can bring new understanding of what we need and want in terms of sexual fulfillment.

Baby boomers have changed society as they have passed through life stages and changing times. Following the sexual revolution of the 1960s and 1970s, can we expect that these adults will place greater emphasis on their sexual identities or on meeting sexual needs than previous residents of nursing facilities?

Nursing homes and residential care facilities are often places where discussion of sexuality is taboo. Residents are told to consider these facilities “home” for a period of their lives. However, in contrast to what is private behavior in one’s own home, sexual behavior in one’s “nursing home” may be perceived as a problem for other residents, staff and families. Staff members must respect the residents’ rights despite their own biases or values. Family members may have to confront their loved ones as sexual beings, even when it is uncomfortable to do so. Ethical holistic quality care and treatment must acknowledge biological, psychological, social, emotional and spiritual components of an individual’s life.

How can facilities insure freedom of expression while protecting residents and staff from abuse or unfair judgment? Administrators and facility policies must insure compassionate, competent responses to resident sexuality and behavior. How can facilities provide quality medical, nursing and personal care while meeting a resident’s right to privacy? Privacy is further complicated by financial limitations that may necessitate sharing a room with a stranger.

The issues surrounding sexuality in nursing facilities are complex. Flexibility and knowledge are essential to respond to diverse values and varying capacity of individuals to make informed decisions. Sexuality and sexual behavior must be handled with judgment, respect, prudence, and concern for the best interests of the residents.

Consensus on such an intimate and charged topic is highly unlikely. In the absence of definitive research and clinical or best-practice guidelines, experience over time becomes invaluable shared knowledge and wisdom for facility staff and for families of facility residents.

If you would like to contribute to a manual for care staff, family members and persons with AD about sexuality in facility care, please send your story, question or thoughts to:

Duke Family Support Program
c/o Edna Ballard
DUMC Box 3600
Durham, NC 27710

Please indicate if you want your name withheld or cited.

INVOLVEMENT

Tell me and I’ll forget
Show me and I may remember
Involve me and I’ll understand.
Unknown

ACCOMPLISHMENT

It is amazing what you can accomplish
if you do not care who gets the credit.
Harry S. Truman

Where the Self?

(After viewing PBS Special, "The Forgetting")

©Henry Walker, January 24, 2004

the animated images linger behind my eyes,
lurking in the very neurons and synapses Alzheimer's attacks,
on tv I watched him gum up the works
and pull loose the connections
like an assassin methodically working
to find and kill the leader who hides
somewhere within the labyrinth of the mind's pathways,

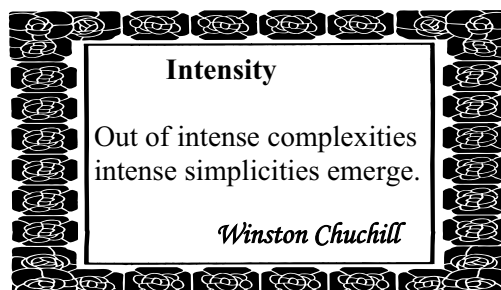
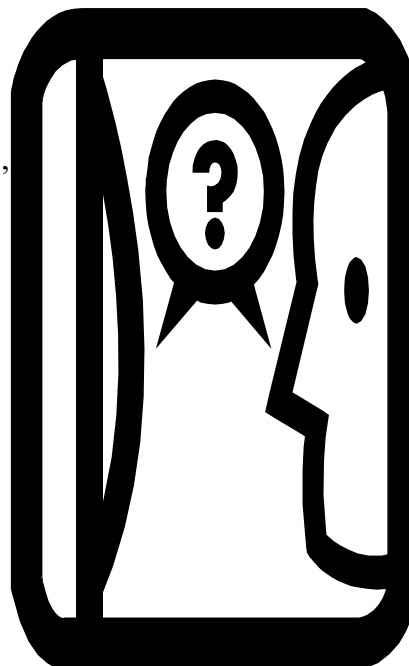
where is the self behind the eyes?
how much of each of us
is the sum of all those connected neurons?
and do we decline in basic self as they slip away?

I offer my mother, my experience and my intuition,
as one answer to the conundrum of self,
and I know somewhere deep behind my eyes
that deep behind her eyes
she's still there,

like a queen retreating high into the last keep
as barbarians take away her outlying regions
and besiege her defenses, step-by-step,

she's lost much of the kingdom she built
with the actions of her life
to which so many of us had access,
but who she is still burns bright
behind the last walls that guard her life and self.

Editor's note: "The Forgetting" and its 30-minute follow-up "Alzheimer's: The Answers You Need" will be re-broadcast on June 16th, 2004 at 8 p.m. EDT. (Check local PBS listings). There will be a simultaneous SAP track in Spanish of the whole two hours. (See Lisa & Edna speak Spanish fluently!).





When Your Partner Disappears . . .and Someone Cares

by Chris Murphy, Charlotte, NC

December, 2003

She is still just as pretty and full of the love I've grown to know for 52 years. Our life has been full of change and excitement, none of which she can recall. I accept this because we can still talk about things that happened, and she pretends to understand when we look at old photos, or when our kids come to visit. We know we have lost her to this terrible disease, but this does not register in a once beautiful mind that could solve complicated problems, impart wisdom to four children, and line up critical putts to win a state women's golf championship.

Now, making the bed is an unfathomable challenge, washing dishes is an unsolvable mystery, and selecting clothes to wear is beyond comprehension. None of the basic day-to-day activities can be done, even with hints, urging and lots of help. She watches television in the evening, but does not comprehend, and she reads the newspaper or a magazine but has no idea what she is reading. She pronounces the words aloud in a light whisper with a slight lisp. But when asked "what are you reading?", she does not know. She has no idea of what day it is, or the month or year. If asked her street address, she does not know, nor does she know the city or state in which we live. But she finds beauty in everything--a tree, the sky, a magazine cover, even the coat a stranger is wearing when we walk at the mall. Many times the stranger will not understand my wife commenting on her coat, but this is awkward for just a moment. When we go to a restaurant, she may stop by a stranger's table and begin a conversation; or if she goes by herself to the rest room, she will get lost. The years our children were growing, she was mentor, example, teacher and role model. Thanks mainly to her, they all grew into productive and capable adults, now with children of their own. I had to travel a great deal during those years, so it was mainly up to her. Our children live in different states. Although they have great sympathy and understanding, they cannot help with the daily challenges. They see the changes when they visit, but they have no idea of the stress and frustration that I feel.

It is interesting how friends and relatives react to her. The people next door have almost stopped speaking because they really don't know how to handle her situation. Our church friends were sympathetic for a while, but the expressions of concern have slowly ebbed away. They are cordial when we attend service, but the offers of help seem to have disappeared. Out of sight, out of mind seems to have replaced the Christian concept. The ladies she used to play golf with no longer stop by to visit or even call. I can understand all this, because people simply do not know how to deal with someone who has Alzheimer's. The person they knew is gone and this new person is a stranger to them with whom they have nothing in common.

It is interesting that people you would least expect will show empathy and caring. A lady who works in a delicatessen where we often have lunch will go out of her way to help us, and shows a genuine concern for my wife. A clerk in a local

department store took great pains to make sure she got a nice looking outfit to wear, and was caring in how she dealt with my wife's lack of understanding. I believe there are special people who sense that someone like my wife is going through a difficult time and they can show compassion at the right time.

She enjoys going to public places and watching people. Many times her comments about someone's weight, appearance, or actions will be too vocal and there have been some embarrassing moments. But I know it is not her talking, because the sweet, loving person that I remember would not do this. I have learned that correcting her is not the thing to do because she does not understand, so I try to divert her attention to something else.

She loves music, and surprisingly can sing along with many of the old songs, even harmonize with the vocalists. So, we keep our radio tuned to a station that plays all the Golden Oldies. This also seems to keep her from thinking that she needs to call her mother, who passed away 32 years ago, or wondering who those people are in another room when no one is there.

I have watched her decline for the past five years and have managed to keep up with this new person in my life, but time brings on new responsibilities and demands. I have had to change priorities and so the time I have for my personal activities has changed to accommodate her requirements. I can no longer say, "be back in about an hour," in order to take care of some business. This is frustrating because there are things I need to do and I either have the option of not doing them or simply taking her along. This is difficult to do when a business friend asks me to lunch to get my advice on a business problem.

I believe it was something akin to a divine plan when I met Marsha Ghent, who is a caregiver support specialist with the Mecklenburg County Government. Interestingly, it was my son, who lives in Mississippi, who found out from the internet that such an activity exists in my county. Marsha's genuine concern and the respite care that they have provided has saved my sanity. Because of their help I have been able to resume teaching at the University and to continue some of the research I had put on hold. Because of them I can be productive, and hopefully some of the students I am teaching will benefit because I am able to be there.

The future is a mystery. A new drug for Alzheimer's will be available in January and the doctor at Duke University says he will make it available to her. The promise that this may restore part of her memory is our greatest hope. She has been in a clinical study program there for about a year. It is possible that the result of this study program will at least benefit someone in the future. Knowing there is no cure makes you grasp at threads of hope. Being part of a clinical study program that could bring a cure for this disease that could bring hope to others would be more than gratifying.

I am not one to offer advice to others who appear to be in my situation, because every situation is different. That is why I gave up on support groups. The complaining and reiteration of symptoms by the other caregivers is discomfoting. I prefer going to a lecture by a professional, or to a panel discussion. I like to hear about research and what is going on in other parts of the world to counter this terrible disease. In all cases I bring my wife with me because we are a team in this thing, and even though she does not understand or

comprehend what is being said, she is the object of the discussion and should be involved.

Finally, we make it a point to do something social every week; go to a movie, walk the mall or go out to dinner. We call it our date and I know she enjoys it. It is the mixing with other people that keeps her involved. While she doesn't remember what we did by the time we get home, or what the movie was about, being with other people is part of our humanity. Then, there is always the chance we will meet a person, like the lady at the deli, who does care.

What Does Love Mean?

Professionals asked 4-7 yr. olds on Valentine's Day to address the question, "What Does Love Mean?" Two telling responses follow:

"Love is like a little old woman and a little old man who are still friends even after they know each other so well." Six-year-old boy.

"You really shouldn't say 'I love you' unless you mean it. But if you mean it, you should say it a lot. People forget." Eight-year-old girl.

Spirit

©Emily Albera, Bath, NC

November, 2003

When she dies, you'll say her body is a shell of her former self;
The spirit is all that remains.
I hope I can believe you.

This frail body teeters as she walks.
Skinny fingers shake as she gropes for stability.
Basic instincts tell her she must not fall—
Such tenacity at ninety-nine.

Why I see beauty in her frailty, I do not know.
Perhaps it's her history—always fighting in spite of the odds,
Always believing when others doubted.

Tell me her weak body is going to a better place
And that I can survive her demise.
I will try to believe.

I will try to remember the spirit I see in her face right now
And not selfishly miss her body.

I will remember her spirit.
I will eventually release her body,
But it'll be hard.



Postscript: Emily's mother died on November 13, 2003 in her home, just three months before her February 17, 2004 100th birthday. Despite her intense grief, Emily attended the Bryan ADRC's 18th Annual Conference in February with her mother's faithful companion, Liz. These three remarkable women presented their genuine partnership for successful home care at a previous Bryan ADRC Conference close to her mother's 95th birthday.



Have You Heard About?

- Weiss B. (2004). When the Doctor Says "Alzheimer's": Your Caregiver's Guide to Alzheimer's & Dementia. Bloomington IN: 1st Books Library. Paperback ISBN 1-4107-4140-0. A wife's perspective.
- Managing Nutrition in Dementia Care: A Supportive Approach for Caregivers. (2001). Available from Alzheimer's Association – Western NY Chapter. www.alzwny-org or from NC's Western Carolina Chapter. 800-888-6671.
- Rudin L & G (Eds). (2003). What If It's Not Alzheimer's? Amhurst, NY: Prometheus Books paperback. (716) 691-0133x207. ISBN 1-59102-087-5. Information on frontotemporal dementia from a family perspective.
- Asher, E. (Ed.). (2003). A Bridge of Hope: A Collection of Inspirational Poems & Testimonies for Caregivers. Gainesville, GA: Legacy Link CARE-NET. \$6.00 check to Legacy-Link CARE-NET c/o E. Asher, 5325 Raintree Trail, Oakwood, GA evasher@aol.com.
- Miller S. (Knopf, 2003). The Story of My Father: A Memoir. A novelist-daughter's perspective.
- Beedle J. (rev. edition, 1999). The Carebook: A Workbook for Caregiver Peace of Mind Deluxe version (\$24.50) and Economy version (\$8.50) The Carebook, 6622 SE 108th Street, Portland, OR 97266. (503) 760-5750.
- Mittelman MS, Epstein C, Epstein PH. The Alzheimer's Healthcare Handbook. Essential information for anyone involved in the care of a family member with Alzheimer's disease. Marlowe & Co., \$14.95. ISBN 1-56924-445-6.
- American Health Assistance Foundation. Fading Memories—An Adolescent's Guide to Alzheimer's Disease. \$5.00. 1-800-437-2423 or www.ahaf.org.
- Johnson KD. (2003). Financial Crimes Against the Elderly. Washington DC: US Department of Justice Office of Community-Oriented Policing Services. 74pp monograph (800) 421-6770 or www.cops-usdoj.gov.
- Hospice Foundation of America (2004). Living with Grief: Alzheimer's Disease. (Kenneth J. Doka, Ed.). (800) 854-3402 or www.hospicefoundation.org
- American Geriatrics Society. (2004). Geriatrics at Your Fingertips. 6th Edition. Free on-line access. www.geriatricsatyourfingertips.org
- American Psychiatric Publishing (2004). Textbook of Geriatric Psychiatry. 3rd Edition. (Blazer DG, Steffens DM and Busse EW, Eds.) Washington, DC ISBN 1-58562-065-3.
- Koenig Coste, J. (2003) Learning to Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease. An experienced nurse and wife of a man who died with AD.
- Lindbergh, R. (2002) No More Words: A Journal of My Mother, Anne Morrow Lindbergh. New York: Touchstone paperback. \$12.00 End-of-life powerful family story.
- Elias MF, Sullivan LM, D'Agostino RB et al. (2004) Framingham Stroke Risk Profile and Lowered Cognitive Performance. Stroke: Journal of the American Heart Association. Vol. 35: p. 404. <http://stroke.ahajournals.org>.
- Karlawish JH, Casarett DJ James BD et al. (2003) Why would caregivers not want to treat their relative's Alzheimer's Disease? JAGS 51 (10): 1391-7.
- Alzheimer's Assn. Steps to Understanding Financial Issues-Resources for Individuals with Alzheimer's Disease. 23 page pamphlet. Call 800-279-3900.
- Consumer Reports. November, 2003. Do you need long-term-care insurance?



Websites

http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1034. How to assess your care situation; develop a care team; hold a family meeting; access community organizations and private agencies; and balance work and caregiving.

<http://www.alzforum.org>. A compendium of information for researchers, physicians and the general public. News, discussion forum, interviews, diagnostic and treatment guide.

<http://www.alzheimers.org>. ADEAR. Maintains information on Alzheimer's disease research, diagnosis, treatment, drugs and clinical trials, Federal Govt programs and resources.

www.dhhs.state.nc.us/aging/ombud.htm. New excellent NC long-term care site.

www.fullcircle_care.org. Best NC caregiver site.

<http://www.nlm.nih.gov/medlineplus/alzheimersdisease.html>. An all-in-one search site. This page provides links to recent news items, symptoms and diagnosis, research, statistics, clinical trials, coping issues and other resources.

<http://www.ALZBRAIN.org/gallery.htm>. Viewable scans of a normal brain and an Alzheimer brain with the areas of memory labeled.

<http://www.webofcare.com>. Short animations demonstrate home safety, infection control, personal care, transfers, incontinence care. Follow the links "Alzheimer's/Dementia" and "Caregiving Skills."

<http://www.rush.edu/patients/radc/pdfs>. See Caregiver's Manual.

<http://www.biostat.wustl.edu/alzheimer>. This site links aging and dementia sites and contains the ALZHEIMER discussion group (an on-line support group for family caregivers and professionals).

<http://www.alz.co.uk>. Alzheimer Disease International (ADI) Information about AD (for the person with AD and the caregiver – in English and in 25+ languages.)

www.kidshealth.org/kid/grownup/conditions/alzheimers--p3.html. Great website explains AD to kids.

www.guideline.gov/summary/summary/.aspx?doc-id=3611. 2003 Guideline on oral hygiene for cognitively impaired older adults.

www.nchealthinfo.org. See Alzheimer's disease websites serving NC.

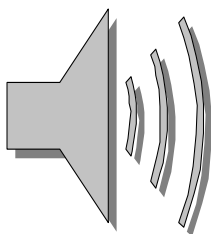
<http://www.yellowpieplate.umn.edu/06-wwa.html>. Innovative program entitled "Who Gets Grandma's Pie Plate?" Helps families make decisions regarding inheritance.

www.apa.org/releases/mind_article.pdf. How the Mind Hurts and Heals the Body.

www.pbs.org/theforgetting. See The Living Center for people with dementia and their families.

www.witn.psu.edu/articles/article.phtml?article_id=6. What's in the News: Music Therapy. 2003. Excellent review of benefits of music for people with dementia.

www.dhhs.state.nc.us/aging/drugs.htm. NC Division of Aging and Adult Services. Resources for Assistance with Prescription Drugs. 2 pages Updated 2/7/04.



Hope
We must accept finite disappointment
But we must never lose infinite hope.
Martin Luther King

Duke Family Support Program
Duke University Medical Center
Box 3600
Durham, North Carolina 27710
Phone: 919-660-7510
(In NC 800-672-4213)
www.dukefamilysupport.org



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